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The association between patient attitudes and values with strength of consideration for contralateral prophylactic mastectomy in a population-based sample of breast cancer patients

Sarah T. Hawley, PhD, MPH¹, Kent A. Griffith, MS, MPH², Ann S. Hamilton, PhD³, Kevin C. Ward, PhD, MPH⁴, Monica Morrow, MD⁵, Nancy K. Janz, PhD⁶, Steven J. Katz, MD, MPH^{7,*}, and Reshma Jagsi, MD, DPhil^{8,*}

¹University of Michigan, Department of Internal Medicine, Division of General Medicine, Veterans Administration Center for Clinical Management Research, Ann Arbor VA Health Care System, Ann Arbor, MI

²University of Michigan, Center for Cancer Biostatistics, School of Public Health, Ann Arbor, MI

³Keck School of Medicine, University of Southern California, Los Angeles, CA

⁴Emory University, Rollins School of Public Health, Department of Epidemiology, Atlanta, GA

⁵Memorial Sloan-Kettering Cancer Center, Department of Surgery, New York, NY

⁶University of Michigan, Department of Health Behavior and Health Education, School of Public Health, Ann Arbor, MI

⁷University of Michigan, Department of Health Management and Policy, School of Public Health, Department of Internal Medicine, Division of General Medicine, Ann Arbor, MI

⁸University of Michigan, Department of Radiation Oncology, Center for Bioethics and Social Science in Medicine, Ann Arbor, MI

Corresponding Author: Sarah T. Hawley PhD MPH, Professor of Medicine, Health Management and Policy & Health Behavior and Health Education, University of Michigan, Ann Arbor VA Center for Clinical Management Research, North Campus Research Complex, 2800 Plymouth Road, 4th Floor, sarahawl@umich.edu, (734) 936-4787 (phone).

*These authors contributed equally to this work

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Author contributions

Sarah Hawley: Conceptualization, methodology, investigation, writing-original draft, writing-review and editing, visualization, funding acquisition

Kent Griffith: Methodology, investigation, software, formal analysis, writing-original draft, writing-review and editing, and visualization

Ann Hamilton: Conceptualization, methodology, investigation, writing-original draft, writing-review and editing, and project administration

Kevin Ward: Conceptualization, methodology, investigation, writing-original draft, writing-review and editing, and project administration

Monica Morrow: Conceptualization, methodology, investigation, writing-original draft, and writing-review and editing

Nancy Janz: Conceptualization, methodology, investigation, writing-original draft, and writing-review and editing

Steven Katz: Conceptualization, methodology, investigation, writing-original draft, writing-review and editing, visualization, project administration, funding acquisition

Reshma Jagsi: Conceptualization, methodology, investigation, writing-original draft, writing-review and editing, visualization and funding acquisition

Abstract

Background—Little is known about how the individual decision styles and values of breast cancer patients at the time of treatment decision making are associated with consideration of different treatment options, specifically with consideration of contralateral prophylactic mastectomy (CPM).

Methods—We identified newly diagnosed patients with early-stage breast cancer treated in 2013–14, identified through SEER registries of Los Angeles & Georgia, and surveyed them about 7 months after surgery (N=2578, RR=71%). The primary outcome was consideration of CPM (strong vs. less strong). We assessed the association between patients' values and decision styles and strong consideration using multivariable logistic regression.

Results—About one quarter (25%) of women reported strong/very strong consideration of CPM, and another 29% considered it moderately/weakly. Decision styles, including “rational-intuitive” approach to decision making, varied. The factors most valued by women at the time of treatment decision making were: avoiding worry about recurrence (82%), and reducing the need for more surgery (73%). In multivariable analysis, patients who preferred to make their own decisions, those who valued avoiding worry about recurrence, and who valued avoiding radiation significantly ($P<0.05$) more often strongly considered CPM, while those reported being more “logical” and who valued keeping their breast less often did so.

Conclusions—Many patients considered CPM, and consideration was associated with both decision style and values. The variability in decision style and values observed in this study suggests that formally evaluating these characteristics at or prior to the initial treatment encounter could provide an opportunity for improving patient clinician discussions.

Keywords

breast cancer; contralateral prophylactic mastectomy; population-based survey; decision-making; decision styles

INTRODUCTION

The surge in use of contralateral prophylactic mastectomy (CPM) after diagnosis of breast cancer has motivated interest in understanding how the treatment decision-making process can drive patient desire for aggressive procedures that increase morbidity in the absence of a survival benefit. CPM has increased from relatively few among women who do not have an elevated risk of developing a second primary breast cancer to a rate of over 20% in this population and now represents about half of mastectomy performed for breast cancer in the United States.^{1–3} Importantly, many more women consider getting the procedure than actually receive it.

Remarkably little research has been done to examine the psychological factors that drive patient desire for CPM. Several studies that have examined correlates of the use of CPM have observed that the procedure is received primarily by more highly educated, Caucasian, and insured patients.^{2–7} Research that has explored the patient perspective has found women's choices for the procedure to be driven by worry about recurrence and desire for

“peace of mind” as well as the desire for better cosmetic outcomes.^{2,5} However, this literature has been limited by a focus on the characteristics of patients who ultimately receive CPM. Indeed, very little is known about all patients who think seriously about receiving CPM, including those who do not ultimately receive it. Surgeons must be able to identify this much broader group of women whose concerns must be addressed as part of the treatment decision making process.

To address this gap in the literature, our study had two objectives. First, we characterized patient perspectives about the importance of different factors related to treatments (values) and underlying attitudes toward decision-making (decision styles) in a large, diverse, population-based sample of patients with early-stage breast cancer at average risk of development of a second primary cancer. Second, we evaluated correlates of strong consideration of CPM, including patient decision style and values.

METHODS

Study Population

The iCanCare Study, a large, diverse, population-based survey study of women with favorable prognosis breast cancer, accrued women ages 20–79 with newly diagnosed breast cancer (DCIS and stages I–II, <5cm in size) as identified by rapid reporting systems from the Surveillance Epidemiology and End Results (SEER) registries of Georgia and Los Angeles County in 2013–2014. Black, Asian, and Hispanic women were oversampled in Los Angeles.⁸ We selected 3,880 of whom 249 women were later deemed ineligible due to having a prior cancer diagnosis or stage III or IV disease; residing outside the SEER registry area; being deceased, too ill or unable to complete a survey in Spanish or English. Of 3,631 eligible women remaining, 1,053 did not return mailed surveys, refused to participate or were lost to follow up. Among the 2,578 respondents (71%), 216 were excluded due to having bilateral disease and/or being a genetic mutation carrier as reported on the survey. The resulting analytic sample was 2,362 women (Supplementary Figure 1).

Data Collection

Patients were sent surveys approximately 2–3 months after surgery, with median completion time 6–7 months post surgery. We provided a \$20 cash incentive and used a modified Dillman method for patient recruitment.⁹ All materials were sent in English and Spanish to those with Spanish surnames.⁸ Survey responses were then merged with clinical data from SEER. The study was approved by the Institutional Review Boards of the University of Michigan, University of Southern California, and Emory University.

Questionnaire Design and Content

Patient questionnaire content was guided by a conceptual framework, research questions, and hypotheses. We chose established measures when available and developed new measures when necessary, drawing from the literature and our prior research.^{10–12} We used standard techniques to assess content validity, including review by survey design experts, cognitive pre-testing with patients, and pilot studies in selected clinic populations.

Measures

Primary Outcome: Consideration of CPM—We asked women to indicate on a 5-point Likert Scale how much they considered having a mastectomy on their unaffected breast (from not at all to very strongly). We looked at any consideration (weakly, moderately, strongly, or very strongly) vs not at all, as well as categorization into 2 groups: strongly/very strongly vs other groups. For all but our initial descriptive analyses of this variable, we focused on the latter dichotomized comparison.

Key Independent Variables

Decision Style Factors—We used four measures designed to assess women's underlying approach to decision-making (decision-styles) based on prior work.

Decision Making Apprehension Scale: This scale consisted of 4 items, each on a 5-point Likert Scale (not at all to almost always), designed to assess how women normally approach the emotional side of decision-making: a) I worry about making a bad decision, b) I struggle to decide what the right decision is, c) Once I make a decision, I don't look back, and d) I worry a lot about the outcomes of my decisions. The Cronbach alpha for the scale was 0.78 and it formed a single factor with higher scores indicating more decision-making apprehension.

Decision Making Traits: We asked 5 questions to assess the degree to which women indicated they were usually more rational or more intuitive in their approach to general decision-making based on literature in decision psychology.¹³ The items each had a 4-point Likert-like scale: 1) did you rely on your instincts and feelings or weigh the pros and cons (1 – instincts to 4 – pros and cons); 2) Were you more intuitive or more rational in your thinking? (1-more intuitive to 4- more rational); 3) Did you really think things through or did you go with your first instinct? (1 – went with my first instinct to 4- thought things through); and 4) Did you spend a lot of time reviewing the details or did you make decisions quickly? (1- quick decisions to 4-review details), and 5) Did you do what seemed most logical or did you just follow your heart? (1- follow heart to 4-more logical). Each of these items was dichotomized.

Decision Autonomy Preference: We asked 2 questions to assess desired role in decision-making. They were asked to indicate the degree they wanted their doctor to tell them what to do, and the degree to which they preferred to make their own breast cancer treatment decisions, each on 5-pt scale from not at all to all the time. Each was categorized into (quite a bit/all the time) vs less.¹⁴

Patient Values

We assessed the women's reports of the importance of sixteen underlying values related to breast cancer treatment. For each value, we asked women to indicate how important it was to her at the time of making her treatment decision on a 5-point Likert Scale (from not at all to very important). For analysis, an indicator was created for reporting "very" or "quite" important vs. other categories.

Covariates

Covariates used in this analysis included patient demographics obtained from the patient questionnaire. We included age, race/ethnicity (White, Black, Latina, Asian, Other/Unknown), educational attainment (high school graduate or less, some college or more), marital status (married/partnered vs. not), income group (<40K, 40-<90K, >90K), insurance status (Private, Medicare, Medicaid, other, none), bra cup size (A/B, C, D, DD+) and family history of breast cancer (none vs. 1 or more first degree relatives). We also included whether the patient reported having had an MRI (yes/no/missing). Stage (0, I, II) was collected from SEER. An indicator of high risk for having a genetic mutation was created from both patient report and SEER variables, as described in other work.³ Geographic site (GA or LA) was also included to account for regional differences.

Statistical Analyses

We first calculated the proportion of women who considered CPM strongly or very strongly (hereafter referred to as “strong consideration”) overall, and by all demographic and clinical factors, including risk status. We generated descriptive statistics of each decision style measure, and for all 16 values overall, by generating the proportion indicating quite/very important for each value. We then evaluated associations between these measures and strong consideration of CPM after adjusting for the covariates noted above.

Multivariable logistic regression was used to explore correlates of strong consideration of CPM, including decision style factors, values and covariates that remained significant at $P < 0.05$ in the adjusted analyses. Parsimonious multivariable models were constructed using backward selection techniques using a three step approach. First decision style factors and values were modeled separately each along with all demographic and clinical factors to determine important decision style factors and values. Second, significant decision style and values from each model were then modeled simultaneously again retaining all demographic and clinical factors. Finally, significant decision style factors, values, demographic and clinical factors were retained to arrive at the final parsimonious model. This model was adjusted for clustering at the surgeon level to account for potential surgeon-level practice attributes that may impact patients’ consideration of CPM, such as the availability of or propensity to refer to reconstructive surgeons.^{15–17}

All statistical analyses incorporated weights to account for differential probabilities of sample selection and non-response. Survey and SEER item non-response was low (<5%) for all covariates. We compared the distributions between non-respondents and respondents for age, race, stage and site. White patients (vs. minorities) and those with stage I cancer (vs. stage II) were significantly more likely to respond, which was then addressed by weighting to ensure that the analyses were representative of the original population.

To correct for the potential of bias due to missing data, values for missing items were imputed using sequential multiple imputation (SMI).^{18,19} Five multiply imputed datasets were analyzed and model estimates combined to account for additional uncertainty due to imputation. Results were compared between SMI analyses and complete-case analyses for any meaningful differences. Odds ratios (OR) with 95% confidence intervals (CI) are

reported for models, with p-values 0.05 considered significant. All analyses were performed using SAS version 9.4 (Cary, NC).

Results

Sample Characteristics

The characteristics of the sample overall and by degree of consideration of CPM are provided in Table 1. Mean age was 62 (SD 11) years. Overall, 25% of patients had DCIS, 47% Stage I disease, and 25% Stage II disease. Slightly over half were White (54%); 430 (18%) were Black, 413 (14%) Latina, and 205 (9%) Asian. Most had some college or more educational attainment (72%). The majority (1260, 54%) had private insurance, but 682 (29%) had Medicaid and 328 (13%) Medicare. A quarter (24%) reported having a first-degree family member with breast cancer. Most (71%) were not at high risk for a second primary breast cancer.

Overall, about one quarter (25%) of women reported strong or very strong consideration of CPM, and another 29% considered it moderately or weakly. Of those who considered it strongly, 13% received unilateral mastectomy and 16% breast conservation. In bivariate analyses, women who considered CPM strongly/very strongly were younger, more educated, white, had private insurance, and had a family history of breast cancer, and more often from Georgia.

Decision styles

The mean score on the decision apprehension scale was 2.5 (range 1–5, from not very to very apprehensive). More than half of respondents reported that they were more rational than intuitive (75%), more often thought through decisions than went with their instinct (78%), more often reviewed details than made quick decisions (61%), and were more logical than following their heart (83%) in their approach to treatment decision-making. Over half (59%) indicated they wanted their doctor to tell them what to do quite/all the time, and just over one third (37%) reported that they preferred to make their own decisions quite a bit/all the time.

Values

There was considerable variation in the factors valued by patients in making treatment decisions. Figure 1 shows the % of patients who indicated each value or value group was “very or quite important” to them in making their treatment decision. The most common value women reported being quite/very important was allowing them to avoid worry about the cancer coming back (82%), followed by reducing the need for more surgery (73%), being the newest, most advanced treatment (69%), and avoiding treatment side effects (67%). The least commonly reported to be quite/very important was to have the same treatments as other women had received (23%).

Factors associated with Strong/Very Strong Consideration of CPM

Table 2 shows the odds ratios for associations between individual decision style and values and strong consideration of CPM, after adjustment for the patient demographic and disease

characteristics in separate regression models. Having higher levels of decision apprehension was modestly associated with strong consideration (OR: 1.14; 95% CI 0.99–1.31), while women who reported more logical approaches to decision-making were less likely to have strong considered CPM (OR: 0.52; 95% CI 0.31–0.71). Women who preferred their doctor make the decision less often strongly considered CPM (OR: 0.69; 95% CI 0.55–0.87), while women who preferred to make their own treatment decisions more often strongly considered CPM (OR: 1.74; 95% CI 1.39–2.18). Several values were significantly associated ($P < 0.01$) with strong consideration of CPM, including women who said the following were quite/very important at the time of treatment decision making: avoiding worry about the cancer coming back, avoiding exposure to radiation, requiring fewer trips back and forth for treatment, and choosing treatments that were most extensive. Conversely, women who said that choosing treatments that were least extensive, allowed them to keep their natural breast, were the same treatments as other women had were significantly ($P < 0.001$) less likely to strongly consider CPM.

Figure 2 displays a forest plot showing the multivariable parsimonious logistic regression results for strong consideration of CPM, adjusted for clustering at surgeon level. Patients who had a family history of breast cancer and a larger breast cup size had higher odds of strong consideration of CPM than their counterparts (OR: 2.19; 95% CI 1.65–2.91, OR 1.76; 95% CI 1.17–2.65, respectively), while those from Georgia had lower odds (OR: 0.60; 95% CI 0.42–0.85). Latina women also reported strong consideration of CPM more often than white women (OR: 2.14; 95% CI 1.37–3.34), while African American women reported strong consideration of CPM less often than white women (OR: 0.63; 95% CI 0.43–0.93). Two decision styles remained significantly associated with strong consideration of CPM in the multivariable model: women who preferred to make their own treatment decisions more often strongly considered CPM (OR: 1.56; 95% CI 1.21–2.01), while women who reported being “more logical” in their decision making less often strongly considered CPM than those who reported “following their heart” (OR: 0.50; 95% CI 0.34–0.72). Three values remained significant: avoiding worry about the cancer coming back (OR: 2.26; 95% CI 1.40–3.66), avoiding radiation exposure (OR: 2.85; 95% CI 2.19–3.68) were both associated with strong consideration, while allowing you to keep your natural breast was significantly and inversely associated with strong consideration of CPM (OR: 0.12; 95% 0.08–0.17)

DISCUSSION

In this large, diverse, population-based sample of newly diagnosed breast cancer patients with favorable prognosis, we found considerable variation in both the manner with which patients reported approaching treatment decision making (decision styles) as well as in what women valued at the time of treatment decision making; while most strongly valued avoiding worry about the cancer coming back, other factors were also important to many women. We further found that nearly a quarter of women strongly or very strongly considered having their unaffected breasts removed as part of treatment for their breast cancer, and another 29% considered it moderately or weakly. Our study contributes to the literature about the rise in CPM by deconstructing the decision-making process. Prior to receipt of CPM, all patients must move through a process of weighting the treatment options and consider how the procedure aligns with their values. Factors associated with

consideration, particularly strong consideration, are potentially actionable targets for education and intervention.

Importantly, our results suggest that “values” matter slightly more than underlying personality traits in determining who strongly considers this procedure, though some decision styles were relevant. Our measure of decisional apprehension—developed to assess the type of person who may be more likely to make a decision for extensive treatment to avoid regretting it later—was notably not significantly associated with strong consideration when other factors were included in our model. Similarly, while most of the “rational-intuitive” items were not associated with strong consideration, women who endorsed being more logical in their decision-making *less often* strongly considered this procedure. This held even when controlling for educational status, further underscoring the importance of this finding across all types of patients. This finding further suggests that having a better understanding a woman’s underlying approach—logical vs. more emotional (i.e., “going with the gut”)—may provide opportunities for individualizing the approach to education about risks and benefits.

We also found that women who reported desiring to play a more active role in decision-making more often strongly considered CPM. This finding is consistent with prior work showing that more involved patients, those who report making patient-driven decisions rather than shared or surgeon-driven decisions, more often chose mastectomy, at a time when CPM was not a widely performed procedure.^{10,11} Our current result confirms that such patient-led decision-making is also associated with consideration of even more extensive surgery than unilateral mastectomy. These findings call into question the notion that simply involving patients in decision making is likely to translate to less overtreatment²⁰. They further suggest that perhaps we need to refocus efforts on targeting patients who desire considerable control in the decision making process, as well as on aspects of decision-making that are not purely rational. The importance of affect in general decision-making has been identified,^{21,22} and highlighted in the seminal work by Kahneman.²³ Our findings support that educational efforts in breast cancer treatment should address the intuitive or affective reaction patients have to the meaning of the diagnosis and the prospects of the arduous treatment course, as well as the cognitive, aspects of decision-making. For instance, recognizing that it is not uncommon for patients to have activated intuitive/affective rather than rational pathways of decision-making, a common psychological shortcut or heuristic.^{23,24} This may require interventions using methods targeted to this end such as providing patient stories, as well as numerical information, to appeal to the emotional nature of this decision.

Several of the values measured in our study were associated with strong consideration in the anticipated direction when adjusting for patient and disease characteristics. When women valued things that would align with receiving more treatment, such as avoiding worry about recurrence, and choosing treatments that were more extensive, they more often strongly considered CPM. Conversely we also found that when women valued things that would align with less surgery, such as keeping their natural breast or choosing treatments that were less extensive, they less often strongly considered CPM.

The importance of these values, which have been identified in prior studies, reinforces the need to address directly patients perceptions of risk of recurrence and their reactions to it,²⁵ as many patients overestimate their actual risk of recurrence following treatment. Furthermore, prior work by our team has shown an association between worry about recurrence and subsequent receipt of CPM.⁴ This is particularly concerning given that CPM does not confer benefit for reducing recurrence risk or on long term survival in the population studied in this analysis (non BRAC1/2 positive, no strong family history of breast or ovarian cancer).^{26–28} Our current finding, that worry is associated with consideration as well as utilization, suggests interventions at the time women are considering their treatment options may be useful. Furthermore, the powerful desire for many patients to avoid radiation motivates the need to ensure they are well educated about the benefits and risks of treatment options that include this modality as an adjuvant.

Aspects of this study merit comment. Strengths of this study include a large, diverse sample, high participation rate, and use of unique patient reported measures. However, the study has some limitations. Patients lived in two geographic regions, so may not represent all U.S. breast cancer patients. We did not have details on some practice factors that might have influenced patients desire for CPM such as information and availability of breast reconstruction options. However, we did control for clustering by surgeon and geographic locations. Finally, associations observed in the study are not necessarily causal.

IMPLICATIONS

Our results have important implications for patient-clinician communication to support individualized treatment decision-making. Many more patients consider having CPM, even in the absence of potential for survival benefit, than actually receive it. Assessing decision style and values of patients at or prior to the initial treatment encounter could provide an opportunity for improving deliberation by tailoring discussion about treatment options to embrace the patient's own style and values. There is a need to better educate patients about misperceptions associated with their values; for instance ensuring they understand the actual risk of recurrence since that value is associated with consideration of more extensive treatment. Our results suggest these are key areas for intervention, even in the context of quality improvement or other initiatives to ensure appropriate use of treatments. These assessments can further help physicians to tailor communications to better target patients who may not wish to defer to physicians and/or those who are engaged in more intuitive than rational decision processes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

DISCLAIMERS

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When making your treatment decision, how important was it that the treatment(s)....

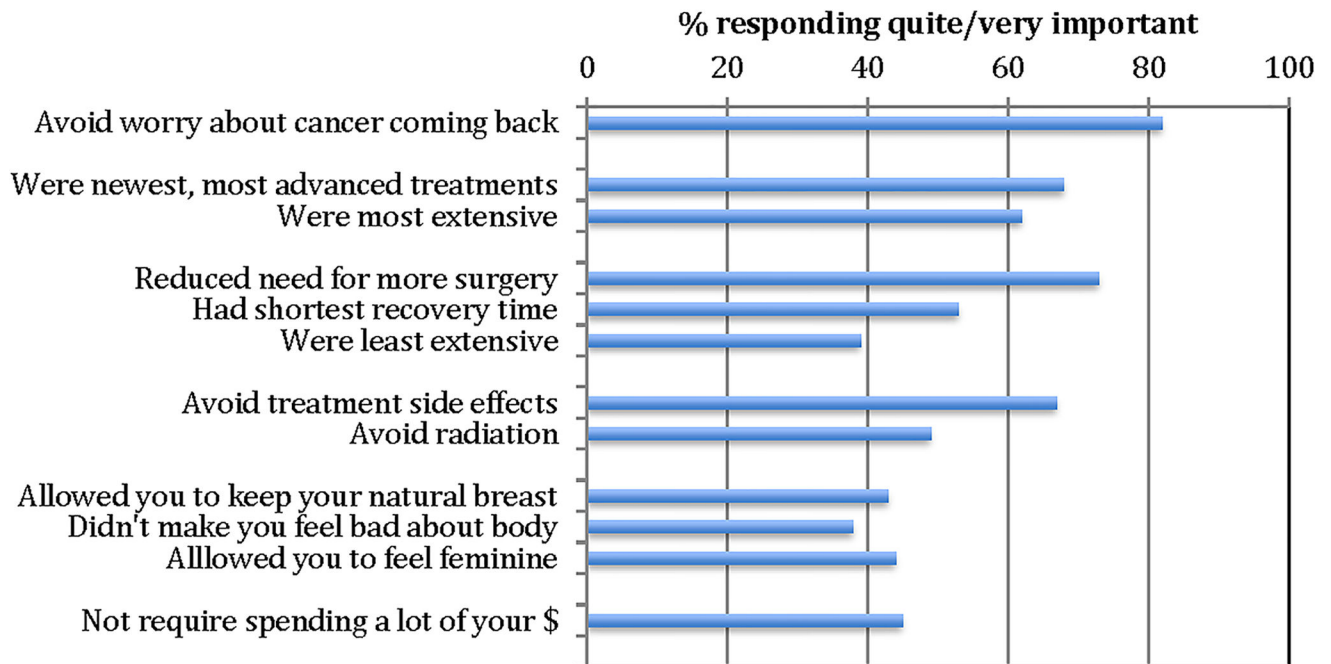


Figure 1.
Patient values in breast cancer treatment decision making

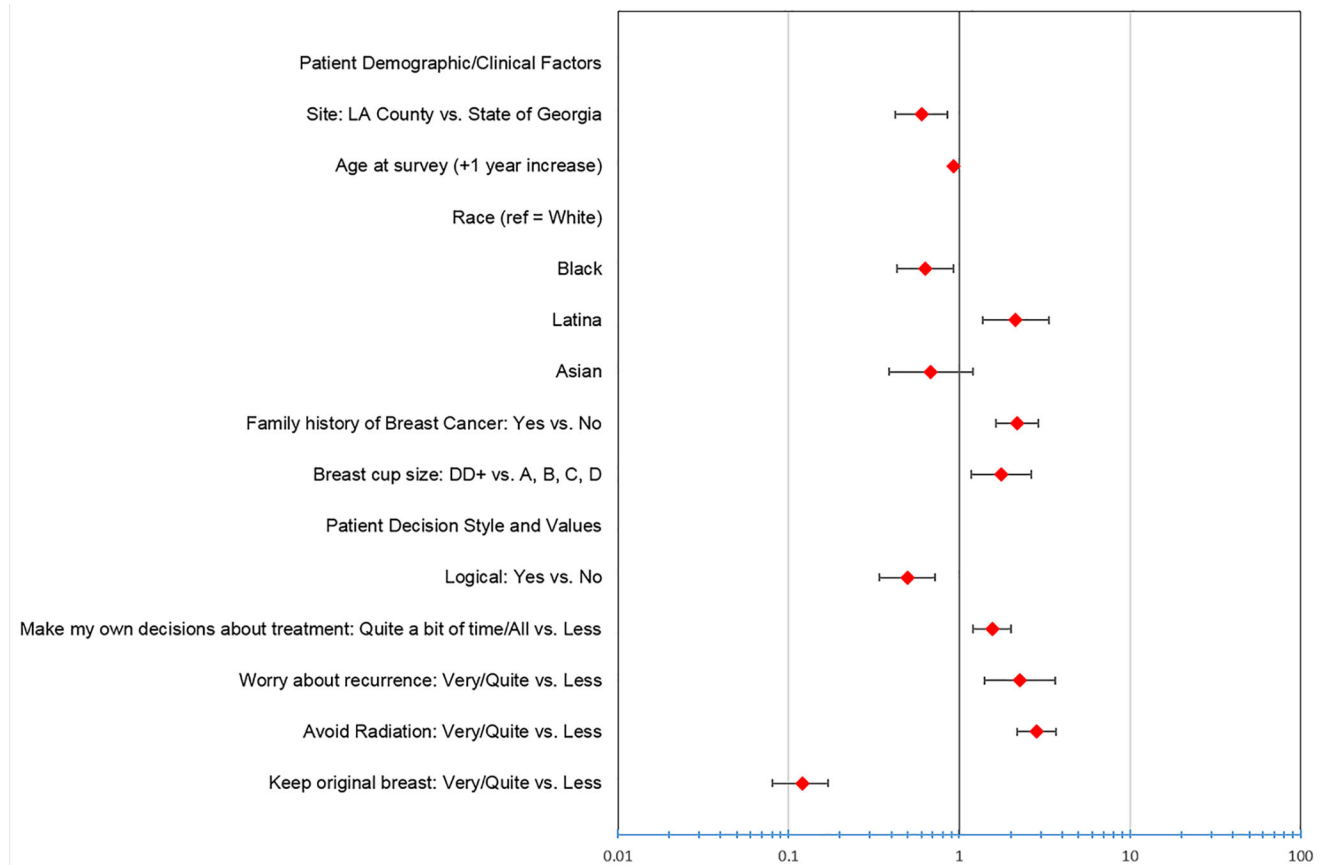


Figure 2.
Adjusted Associations (Odd Ratios) from Multivariate Model Explaining Patients' Strong Consideration of CPM adjusted for clustering at the surgeon level

Table 1

Patient Demographic and Clinical Characteristics (n=2362)

Characteristic	Total (N)	Weighted % or Weighted Mean (SD)	% Strongly Considered
Age at Time of Survey (years)			
Mean age	2,632	61.8 (10.9)	56.4 (11.0)
Study Site			
Georgia	1244	53.9	28.3
Los Angeles County	1118	46.1	19.2
Race/Ethnicity			
White	1273	57.2	25.7
Black	422	18.0	19.4
Hispanic	402	13.6	26.8
Asian	204	8.7	19.3
Other/Unknown/Missing	61	2.5	22.4
Education			
At least some college	1658	71.9	26.3
High school graduate or less	679	27.1	17.7
Missing	25	1.0	33.4
Marital Status			
Married/partnered	1474	62.7	26.1
Not married	859	36.0	20.7
Missing	29	1.3	22.5
Income (annual)			
Less than \$40,000	719	29.3	21.5
\$40,000 – <\$90,000	649	28.3	25.8
\$90,000 or more	579	25.8	28.9
Missing	415	16.6	18.2
Insurance			
Private	1239	53.6	30.3
Other public	30	1.2	25.2
Medicare	672	28.7	14.3
Medicaid	319	12.6	20.7
None	11	0.5	28.0
Missing	91	3.5	20.6
Cancer Stage			
0 - DCIS	425	25.2	23.1
I	1238	46.8	22.9
II	598	24.6	26.8
Missing	101	3.4	27.5

Characteristic	Total (N)	Weighted % or Weighted Mean (SD)	% Strongly Considered
High Risk (for 2nd primary cancer)			
Yes	636	27.3	33.8
No	1668	70.7	20.5
Not known	58	1.9	18.2
Family history breast cancer			
Yes	536	23.4	30.1
No	1650	69.2	21.9
Missing	176	7.4	25.6
Breast Cup Size			
A/B	750	31.9	22.8
C	730	31.0	21.7
D	473	19.7	24.0
DD and greater	339	14.5	31.4
Missing	70	3.0	27.2
MRI			
Yes	1391	59.1	26.7
No	765	32.9	20.2
Missing	206	8.1	20.9

Table 2

Association of decision style and values variables individually with strong consideration of CPM adjusting for covariates*

	OR (95% CI)	P value
Decision Styles		
Decision apprehension scale	1.14 (0.99–1.31)	0.080.
Rational vs. intuitive	1.18 (0.89–1.57)	0.24
Think through vs. first instinct	0.91 (0.68–1.21)	0.48
Review in detail vs. quick decisions	1.09 (0.86–1.37)	0.52
Logical vs. follow your heart	0.52 (0.37–0.71)	<0.001
Prefer to make own decisions (all/most of time vs. less)	1.74 (1.39–2.18)	<0.001
Values		
Avoid worry about cancer coming back	2.27 (1.54–3.35)	<0.001
Reduce the need for more surgery	0.92 (0.71–1.20)	0.54
Avoid side effects of treatment	1.23 (0.96–1.58)	0.10
Avoid exposure to radiation	2.59 (2.03–3.30)	<0.001
Require fewer trips back and forth for treatment	1.51 (1.18–1.92)	<0.01
Did not make you feel bad about your body	1.25 (0.99–1.57)	0.05
Were most extensive possible	1.45 (1.10–1.92)	<0.01
Were least extensive possible	0.70 (0.55–0.91)	<0.01
Allowed you to keep natural breast	0.15 (0.12–0.21)	<0.001
Were the same treatments other women received	0.63 (0.46–0.86)	<0.01
Were the newest most advanced treatments	0.82 (0.64–1.06)	0.13
Had the shortest recovery time	0.77 (0.61–0.97)	0.02
Did not require you to spend a lot of your own money	0.85 (0.67–1.09)	0.20

* adjusted for all covariates included in table 1